



November 16, 2010

To: Illinois Healthcare Reform Implementation Council

From: Sheila Rittenberg, Sr. Director Advocacy & External Affairs
National Psoriasis Foundation

RE: Psoriasis and phototherapy treatment

On behalf of the National Psoriasis Foundation, thank you for the opportunity to submit our comments regarding psoriasis and phototherapy, an effective treatment method that is in decline because of soaring costs to patients. The National Psoriasis Foundation serves about 1.5 million patients a year through programs online and across the country. We are the leading patient advocacy organization in the nation for people with psoriasis and psoriatic arthritis, and are governed by a national Board of Trustees and a Medical Board that is comprised of the country's leading experts in dermatology and rheumatology.

For years, light therapy or phototherapy – one of the oldest and safest treatments for psoriasis – has teetered on the edge of decline because of rising costs shouldered by patients. Over the past months and years, we have received calls and emails from patients who cannot afford these copayments or coinsurance, and have continually heard from dermatologists who cannot keep up their phototherapy practices because demand is in decline.

Although we are excited to be leading this work in Illinois, the road here has been an arduous one. We initially wrote 100 major insurers in the U.S. about the problem. We educated specific health insurers about the consequences of their policies to patients. We spearheaded a letter-writing campaign to several insurance commissioners across the country. The result was always the same: take action at a higher level; pursue legislative change. As a result, we introduced legislation to curb the rising costs of phototherapy for the consideration of the 96th General Assembly in 2010.

Currently we are working to bring stakeholders – patients, health care providers, insurers, and policy makers – together to identify opportunities to find a reasonable solution to the problem of high phototherapy costs. It is in this context that we urge the Illinois Healthcare Reform Implementation Council to address aspects of this issue as you consider the many components of improving our health care system.

As you may know, psoriasis is the nation's most prevalent autoimmune disease, affecting some 7.5 million Americans and an estimated 325,000 in Illinois. About 18 percent of those – or 59,000 Illinois residents – would use phototherapy. The disease most often first strikes between age 15 and 25, and requires steadfast treatment and lifelong attention. We now know that individuals with psoriasis are also at elevated risk for other chronic and serious health conditions such as cardiovascular disease, diabetes, stroke, and malignancies. People with psoriasis are at increased risk for depression and anxiety, and are twice as likely to have thoughts of suicide as



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people without psoriasis or with other chronic conditions. Psoriasis has found to be an independent risk factor for mortality, and in fact people with severe psoriasis die four years younger, on average, than those without the disease.

Unfortunately, even with this profile, psoriasis often is overlooked or dismissed because it does not typically cause death. It is commonly and incorrectly considered by insurers, employers, policymakers and the public as a mere annoyance—a superficial problem, mistakenly thought to be contagious and/or due to poor hygiene. Psoriasis is in fact an autoimmune disease with a genetic basis that starts below the skin surface and can cause severe pain, disability and adverse mental health effects and is associated with a variety of other serious health conditions. Up to 30 percent of people with psoriasis also develop psoriatic arthritis, which without treatment can be potentially disabling and crippling.

What is perhaps most important to understand is that psoriasis is a disease with its own mind. It is individual to each patient and as diverse as people are themselves. Certain psoriasis treatments may work well for some patients but not others. Indeed, a treatment that is effective for one person at one point may prove ineffective over time. There are different factors, such as stress, infection or hormonal changes that may trigger onset or flare-ups. The challenge is for dermatologists to be able to strategize about treatments to ensure that the most appropriate and effective option is being prescribed for a given patient at a given time.

A decade ago, we had far fewer choices in psoriasis treatments than we do today. Fortunately, the set of options has grown. We think of all these treatments – topical creams, phototherapy, oral systemic medications and a newer class of drugs, biologics – as a “toolbox” of options for psoriasis patients. Phototherapy is a form of treatment that provides concentrated doses of ultraviolet light to patients who typically stand in a “light box.” Not every treatment in the toolbox is right for every patient but doctors need **access** to all the available options in order to treat psoriasis effectively. To quote one of our dermatology leaders, “just because you have a screwdriver doesn’t mean you don’t need a hammer.”

Dermatologists have relied on phototherapy for decades as an important and safe treatment modality; unfortunately, the mounting cost to patients is ruling out this option for many. Because multiple visits are required in phototherapy treatment, it can cost thousands of dollars in out-of-pocket expenses. This is because insurance companies require a copayment for each treatment and the amount of these copays is soaring.

The Psoriasis Foundation recently surveyed more than 1,000 dermatologists across the country. Ninety percent of those who responded reported that the high cost of phototherapy copayments, **which can be \$50 or higher per treatment**, limits a patient's ability to undergo this form of treatment.

For many patients who cannot sustain this level of copay, the irony is they are “bumping up” to biologic treatments, which can mean lower patient copays but much higher costs to the system. Compare \$3,500 a year to \$24,000. The first is the typical cost annually of a phototherapy treatment regimen; the second is the average annual cost of a biologic treatment. Yet, a phototherapy patient is paying as much as \$600 a month in copays while a biologics patient may be paying \$10 a month.

The disparity in costs simply does not make sense. And there is a group of patients who is being forced to go directly to biologics because they cannot afford the less expensive, and less invasive

phototherapy. Adding to this, some patients need phototherapy in combination with other treatments – phototherapy is routinely used in concert with topical treatments and also together with biologics.

Mary Gunderson is an example of a psoriasis patient in Illinois who enjoys 80 percent clearance of her psoriasis when she treats with phototherapy. Unfortunately, her copay per treatment is \$45. Mary's doctor prescribed two treatments a week, which keeps her psoriasis under control. However, she cannot afford paying the \$450 every five weeks for the copays – in addition to the \$167 premium she covers every two weeks for her insurance coverage.

Unless the copayment problem is addressed, we are looking at the potential demise of phototherapy - a safe, reliable and relatively inexpensive psoriasis treatment. Patients cannot be expected to pay larger and larger portions of the cost involved in getting this necessary medical care. And doctors cannot be expected to maintain services and facilities that are being used less and less.

In addition to the physical and psychosocial impacts of these diseases, psoriasis and psoriatic arthritis cost the nation an estimated \$11.25 billion annually due to direct and indirect health care costs - with the highest cost being missed work. People with psoriasis, particularly those with moderate to severe disease, have significantly higher health care resource utilization and costs than the general population. Those with severe disease are significantly more likely to be considered "low-income" than those with mild disease and to report psoriasis is the reason they are not working. Furthermore, recent patient surveys indicate that 44 percent of patients, including those with health coverage, have gone without treatment due to financial or insurance issues. The currently unmet medical needs of this population will certainly surface as the Affordable Care Act is implemented. The Illinois Healthcare Reform Implementation Council has the opportunity to proactively address some of the need by curtailing phototherapy costs – a solution with considerable potential for both cost effectiveness and improvement to health related quality of life for patients.

The Psoriasis Foundation is hopeful that the state of Illinois will intervene to reverse the trend of rising copayment costs, allowing people with psoriasis who should be on phototherapy the access to that treatment that they need. We urge the Illinois Healthcare Reform Implementation Council to take action on this issue by:

- Ensuring that health plans participating in the Exchange minimize copays and coinsurance for phototherapy treatment. Patient out-of-pocket costs for management of this chronic condition should not stand in the way of adherence to ongoing medical care and treatment.
- Facilitating continuity of care for low-income patients who may move between Medicaid and private health insurance offered through the Exchange. For patients with Medicaid, it is critical to ensure that a robust network of dermatologists offering phototherapy treatment participate in Medicaid, and continue to provide affordable access for office visits. Patients who move from Medicaid to the Exchange should not have their treatment disrupted by the need to change providers, or by the imposition of unaffordable copayments. For patients with psoriasis, ongoing access to treatment is crucial to controlling the disease so they are able to participate fully in society and in their places of work.

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- Engaging with stakeholders - patients, health care providers, insurers, and policy makers – to raise awareness about the potential cost savings that may be realized by removing barriers to phototherapy treatment and promoting appropriate management of psoriasis and the comorbid conditions that often accompany it.

Thank you again for the opportunity to bring this issue that is important to thousands of people in Illinois to your attention. Please contact me (srittenberg@psoriasis.org, 503.546.8365) if you have any questions or if the Foundation can be of assistance to the Illinois Healthcare Reform Implementation Council.